An iron overload

Sudden bouts of tiredness, sore joints and dry eyes – these are some of the symptoms of haemochromatosis or iron overload. Margaret Hawkins talks to Colm Kavanagh about his diagnosis

Colm Kavanagh from Kiltulla, Athenry, is a part-time farmer who was diagnosed with haemochromatosis (hee-mo-chrom-at-o-sis) or iron overload in 2006. He was 59 at the time.

For years he had been experiencing sudden bouts of tiredness, sore ankles and dry eyes, but put them down to general ageing and computer work.

“The tiredness used to hit me coming in from work or on my way home from work. Many’s the time when I was working in Ballinasloe, 20 miles away, I’d come out and feel so tired that I’d have to pull over to rest,” he says.

Colm used to think that he had a cold or flu coming on when this sudden fatigue hit.

“I used to say to myself that if I lay down for a while I’d recover. When I’d feel better, I’d say I’d overcome that bout, whatever it was. That happened regularly.”

Joint pain also affected Colm then, because of the illness he didn’t know he had.

“My ankles would get quite sore for no reason and I couldn’t understand it. It was like someone suddenly hit me with a stick or a hurley. The leg would nearly go from under me when I was out playing golf, for example.”

DIAGNOSIS SOLVED MYSTERIES

Colm hadn’t a clue that he had haemochromatosis – a condition once called bronze diabetes because patients, in latter stages, had bronze skin.

“I had worked overseas in jobs where medicals would have been very strict, but nothing was picked up until about 10 years ago,” he says.

He regards his diagnosis as “almost accidental”.

“My GP, when I was going in for my usual yearly checkup, decided to do the ferritin test along with the routine ones. That’s how it was found out. I didn’t know the haemochromatosis test existed as I had never heard of the condition.

“The test came back positive and I was told it was bad news but I wasn’t too upset when the full story was explained to me. It certainly solved the mystery of the tiredness and more. My level was about 900 at the time so I had to give blood for six or seven weeks to bring the iron level down.”

REMOVING BLOOD IS ONLY TREATMENT

Removing blood is the only method of removing excess iron from the body and is called venesection or phlebotomy therapy. Colm had never donated blood so this was a whole new experience for him.

“I had hepatitis B years ago so I wasn’t able to give it. I was a bit queasy for the first few bouts but the staff at the clinic were excellent, so after five or six times I’d built up confidence around the process.”

FATIGUE LESSENED – ANKLE SORENESS GONE

There was no instant change in how he felt but over time the bouts of fatigue lessened.

“After a while, I wasn’t getting as tired as often.”

The ankle pain disappeared quickly and his eye dryness problem also diminished.

“My eyes used to be very dry and blood shot and I assumed it was because I was at a computer screen. The eye issue had been worrying me, especially after I’d gone to the trouble of getting protective screens for the computer yet the problem remained – so hearing that dry eyes was a symptom of haemochromatosis explained a lot.”

Colm now uses eye gels regularly to solve the problem.

“I used to really suffer on a sunny day as they would stream and sting and I couldn’t open them. They were bloodshot sometimes, too, and I’d look like I’d been drinking. Now that I know what’s causing the dryness, I use a special eye gel which helps a lot.”

ONE IN 83 IRISH PEOPLE PREDISPOSED

Haemochromatosis or iron overload is one of the most common genetic disorders, particularly in Celtic people. Therefore, when a person is diagnosed, family members should

**Information**

**HAEMOCHROMATOSIS – WHAT IS IT?**

Haemochromatosis is a genetic disorder where an excessive amount of iron is absorbed from a person’s diet. This excess iron is then deposited in the liver, pancreas, heart and in the joints. The iron builds up over the years so the person may be 30-40 years old before symptoms appear.

**THESE SYMPTOMS INCLUDE:**

- Chronic fatigue: tiredness, lethargy.
- Joint pain: generalised aches and pains.
- Abdominal pain: vague and non-specific.
- Sexual dysfunction: loss of sex drive.
- Irregular heart beat.
- Diabetes.
- Hormonal changes.
- Enlarged liver.
- Joint damage.

**NOTE:** Only a doctor should make a diagnosis of haemochromatosis. Symptoms mentioned can also form part of other medical conditions.

**HOW IS A DIAGNOSIS MADE?**

A simple blood test to:

- Check your iron status can confirm or rule out iron overload. It measures:
  - Transferrin saturation – this is the ratio of serum iron to total iron binding capacity.
  - Serum ferritin (an iron storage protein; a raised level of this protein may indicate iron overload).
  - A genetic test for the common mutations will confirm the diagnosis.

**WORDS OF LIFE**

For Christ also hath suffered for sins, the just for the unjust, that he might bring us to God.
be checked too. In Ireland, one in 83 people is predisposed to develop iron overload compared to one in 350 in Europe. Siblings stand at least a one in four chance of being affected.

Colm’s siblings and children* were tested for haemochromatosis after his diagnosis, but luckily none of them have the condition.

**LAZY OR HAD THEY HAEMOCHROMATOSIS?**

Looking back though, Colm suspected that some of his uncles may have had it without knowing.

“A lot of my ancestors died fairly young, mostly of heart attacks. Two grand uncles we used to talk about were reputed to be very lazy and sit by the fire all day, so it’s quite possible they had haemochromatosis. They died aged 56 and 60.

“Knowing what I have now, they could have had haemochromatosis that was never diagnosed.”

Colm helps out during the Irish Haemochromatosis Association (IHA) Awareness Days each year – in Galway shopping centres and at the National Ploughing Championships. He believes that people should be checked for haemochromatosis routinely.

**GET CHECKED FOR IT SO YOU’LL KNOW**

“I think people should be checked for iron overload even if they don’t have the symptoms, given that haemochromatosis is so prevalent in Ireland,” he says. “You’d only need it done once to know if you’re positive or negative. Hopefully once you’re found to be negative then that’s it, the test is done and dusted.”

He thinks doctors aren’t really aware enough of the condition and the need for the test yet.

“I know of people who have tested positive but their siblings and children weren’t automatically tested by their GP for it after their diagnosis. Doctors should immediately tell people to get all their family tested because they could have the same thing as it’s an inherited condition.”

**HOW IS HAEMOCHROMATOSIS INHERITED?**

- “The disease haemochromatosis is a recessive disorder. This means that it only develops if both parents are carriers (one in 25 marriages).
- On average, one in four of the children will develop haemochromatosis, half will be carriers and a quarter won’t.
- If one parent has haemochromatosis and the other is a carrier (about one in 3,000 marriages) then, on average, half of the children will be genetically susceptible to developing haemochromatosis and the other half will be inherited.
- If both parents suffer from haemochromatosis (a rare event occurring in one in 10,000 marriages), all the children will inherit two defective genes and all will be genetically susceptible to developing haemochromatosis.
- Where both parents are carriers, it would be possible for all children to be genetically susceptible to developing haemochromatosis.

**NOTE**

Men will usually show symptoms earlier than women as women lose blood through menstruation.

**TREATMENT**

Early treatment can prevent or stop organ damage, but if damage has already occurred then treatment should halt any further damage and, in most cases, bring about an improvement.

**HOW TAKING BLOOD HELPS**

Every pint of blood removed contains 250mg of iron. The body then uses some of the excess stored tissue iron to make new blood cells which are removed in subsequent phlebotomy. How long the treatment goes on depends on the amount of excess iron in the body at the time of diagnosis. Treatment may mean weekly phlebotomy for one to two years or until the iron levels have been reduced to a safe level. After that, levels are monitored every three months. If levels rise again, phlebotomy is recommended once more.

**DIET TIPS**

The following is advised:

- Modest alcohol consumption.
- No iron medication or multivitamins containing iron.
- No bread or cereals with fortified iron.

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